Letter from the Executive Director

Summer, 2023.

Decisions. Life is but a series of decisions. Most are mundane and inconsequential, such as “What do I wear to work today?”, or “What should I have for dinner tomorrow night?”. Other decisions have the power to define our lives, such as “Should I enlist in the military?”, or “Will you marry me?”. Taken together, the compilation of our decisions, both the ordinary and extraordinary, forge our existence into what our lives become.

There are also those decisions that we don’t make that define us. My eight-year-old son has anxiety issues. So much so that during a recent trip to Dairy Queen he was paralyzed with indecision at the menu board. This didn’t come as a surprise, as his mother and I learned long ago to limit to maybe three different options for him to choose between, or be prepared for a meltdown. Telling him that there was no wrong decision (after all it was Dairy Queen) did not quell his anxiety, on the contrary, it made the situation worse. But when I told him that by making no decision, that also was a decision, he understood what the consequence would be. If he wanted ice cream, he’d have to pick something. Score one Dilly Bar.

I know many people smarter than myself who routinely cannot or will not commit to a decision. Unwillingness to take a position on a matter isn’t limited to people unable to comprehend the ramifications of what a given position might bring. Perhaps it’s fear of a bad decision. Perhaps it’s the erroneous thinking that if you don’t make a decision that’s yours to make, you won’t have responsibility for the results of that decision. I don’t know. What I do know is that some people fail to realize that not making a decision is still making a decision, and that path, also, will have consequences. Tomorrow will come, the results of your decision or indecision will play out, and life will roll on.

That’s great if you get to be the one to choose to make (or not make) a given decision. As executive director, I make many decisions every day, some good, some not so good. Sometimes I even abdicate my decision-making authority to others. At the end of the day, I have chosen what that day’s path through the storyline of my life will look like.

All too often the people in our services, and in services throughout the health care industry, do not get to make those essential decisions, both mundane and monumental, that go on to affect and define their lives. We preach self-determination, individualized services, person centered, but how often do we live up to that creed? Our group homes are our workplaces, but more importantly, they are the homes of people who didn’t get a whole lot of say in what that environment looks like. This extends also into the realm of their emotional environment, i.e., How are they being interacted with, including with regards to their empowerment to make independent decisions.

When we advocate for our residents, do we *really* let them make decisions for themselves? There are some caveats to this freedom of choice, to be sure. As director of the company charged with keeping people healthy and safe, I do have to put some limits on what kind of decisions residents can make. Getting sued for breach of our moral and legal obligations would impact everyone in the company. Personal freewill stops where it begins to negatively impact others.

We also have our choices limited by natural factors such as personal financial resources, acceptance of taxpayer dollars to maintain our existence, familial and cultural influences, legal status to make one’s own decisions, and other factors. That being said, those personal decisions which will go on to define who we are and the sort of life we live have historically been much more limited for our disabled citizens than they are for you and me.

For example: Can a resident with no medical concerns have an occasional beer? How about several drinks in a single binge? Some of us do. How about a relationship with a person of the opposite sex? How about a sleepover relationship with a friend of the opposite sex? Or a sleepover with a consenting member of the same sex? Or wear clothing identified with members of the opposite sex? What is informed consent anyway? What happens when a person’s developmental age is significantly different than their chronological age? Can a 40-year-old male client play with dolls? Can he play with 11-year-old children at the playground?

Obviously, there are lines where we as caregivers need to guide the decision. There are lines we cannot allow to be crossed. There are also lines where we have attempted to impart our moral authority as superior, when in fact we are imposing a moral judgment we have no place to decide. My only to advise to you is this: All people own their lives, and deserve to live one that fills them with purpose, and meaning, and joy. When you decide something for another human being, remember, every decision, great and small, weave together to become another human being’s life story. Make your decision a good one.

Have a great summer!

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